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Dying dementia patients: Too much suffering, too little palliation

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Abstract

Patient suffering is a pathological syndrome traditionally viewed as encompassing psychological distress, spiritual concerns, and various aspects of physical pain. There is insufficient clinical evidence for suffering in dying dementia patients, which may lead to inappropriate evaluation and insufficient palliative treatment. Our objective was to evaluate the suffering of terminal dementia patients over time, from admission to a geriatric ward to the last day of life. The study included consecutive end-stage dementia patients in a general geriatric department of a tertiary hospital. Patients were evaluated weekly by the Mini Suffering State Examination scale (MSSE) which measures many domains related to suffering. Seventy-one patients were studied. Mean survival of patients was 38.0 ± 5.1 days. MSSE increased during hospital stay from 5.62 ± 2.31 to 6.89 ± 1.95 ($p < 0.001$). According to MSSE

scale, 63.4 percent and 29.6 percent of patients died with a high and intermediate level of suffering, respectively. Only 7 percent of the patients died with a low level of suffering. In particular, patients were restless ($p < 0.001$), had pressure sores ($p = 0.01$), and were considered medically unstable ($p < 0.001$). We concluded that, despite traditional medical and nursing care, a large proportion of dying dementia patients experience an increasing amount of suffering as they approach death. New palliative treatment approaches should be developed for these patients.

Key words: dementia, end of life, quality of life, suffering

Introduction

Issues of suffering and appropriate healthcare for dementia patients remain controversial.^{1,2} End-stage dementia patients are those who have lost their ability to respond to the environment, to speak, and ultimately to control movement. For most dementia patients, the end-stage of their disease is protracted.³ Because of the inability of these patients to communicate and to function, it is more appropriate to discuss the degrees of suffering rather than well-being, satisfaction, or quality of life.

The approach to dying in end-stage dementia patients varies in different

cultures and facilities.⁴ Aggressive approaches may include the use of resuscitation measures (including chest compression and intubation), active medical treatment, wide use of antibiotics, and feeding tubes.⁵⁻⁸ A different approach involves hospice-type palliative care.^{1,9,10} Guidelines and key criteria for enrolling dementia patients in hospice have been proposed that limit eligibility only to those patients who are at Functional Assessment Stage (FAST) 7 (i.e., virtually mute and bedridden).¹¹

The primary causes of death recorded by autopsy in dementia patients are pneumonia, cardiovascular events, and pulmonary embolism.¹² Dementia-related conditions such as cachexia and dehydration have also been mentioned as causes of death.¹³ The enumeration of medical conditions may not reflect the level of suffering of these patients, who are typically unable to communicate verbally. Medical staff and family members should be aware of the challenges to measuring pain and suffering in these patients and use objective assessment tools whenever possible. Better evaluation of the level of suffering of end-stage dementia patients may improve medical and nonmedical interventions.

There are very few reports in the medical literature on methods of assessing the level of suffering in end-stage

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Table 1. Mini Suffering State Examination (MSSE)	
Indicators of suffering	Yes (1)/No (0)*
Not calm	
Screams	
Pain	
Decubitus ulcers	
Malnutrition	
Eating disorders	
Invasive action	
Unstable medical condition	
Suffering according to medical opinion	
Suffering according to family opinion	
MSSE score, total*:	

* MMSE score interpretation: Low level of suffering, 0 – 3; intermediate level of suffering, 4 – 6; high level of suffering, 7 – 10.

dementia patients. The purpose of this study was to evaluate the level of suffering in these patients during their final hospital stay using the recently developed MSSE tool.¹⁴

Patients and methods

We prospectively studied 71 end-stage dementia patients admitted to the long-term geriatric ward of a tertiary

medical center. All patients were referred from acute care departments of the hospital during a 24-month period. Follow-up continued to the date when the patients were discharged or died.

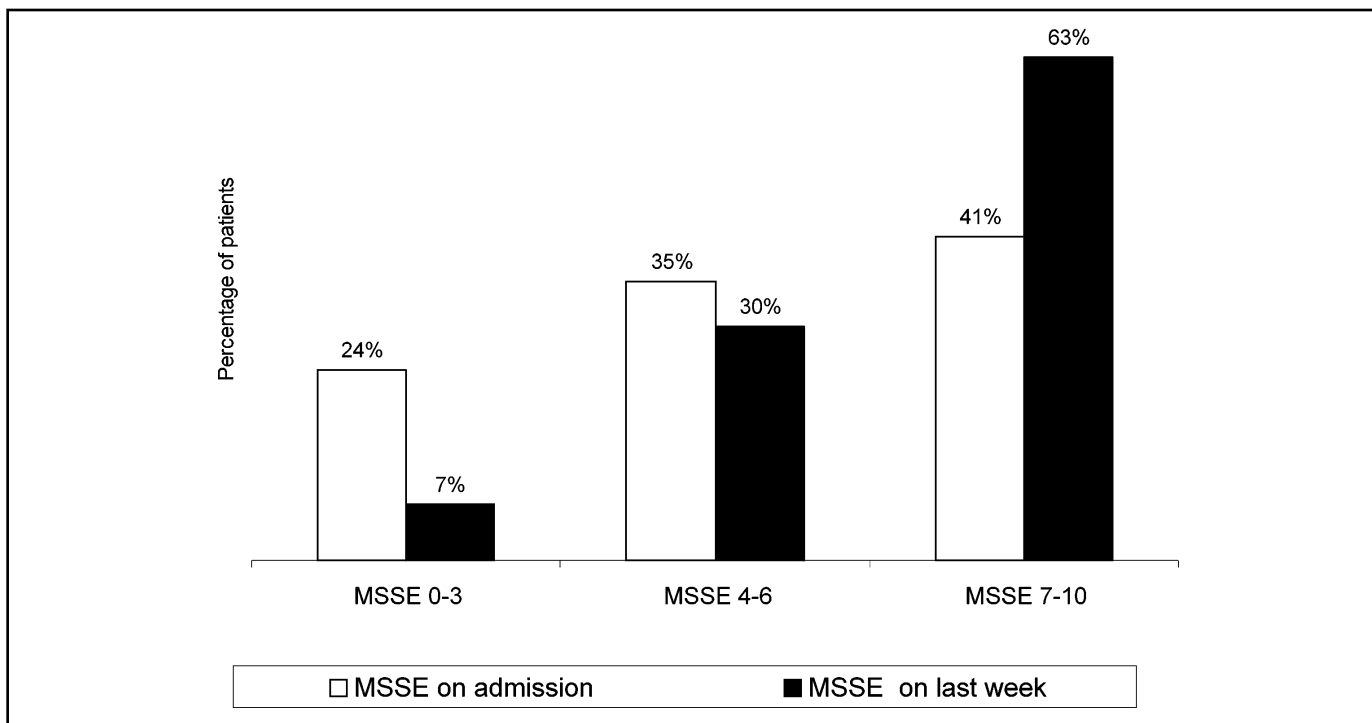


Figure 1. Change in distribution of patients for each MSSE score group.

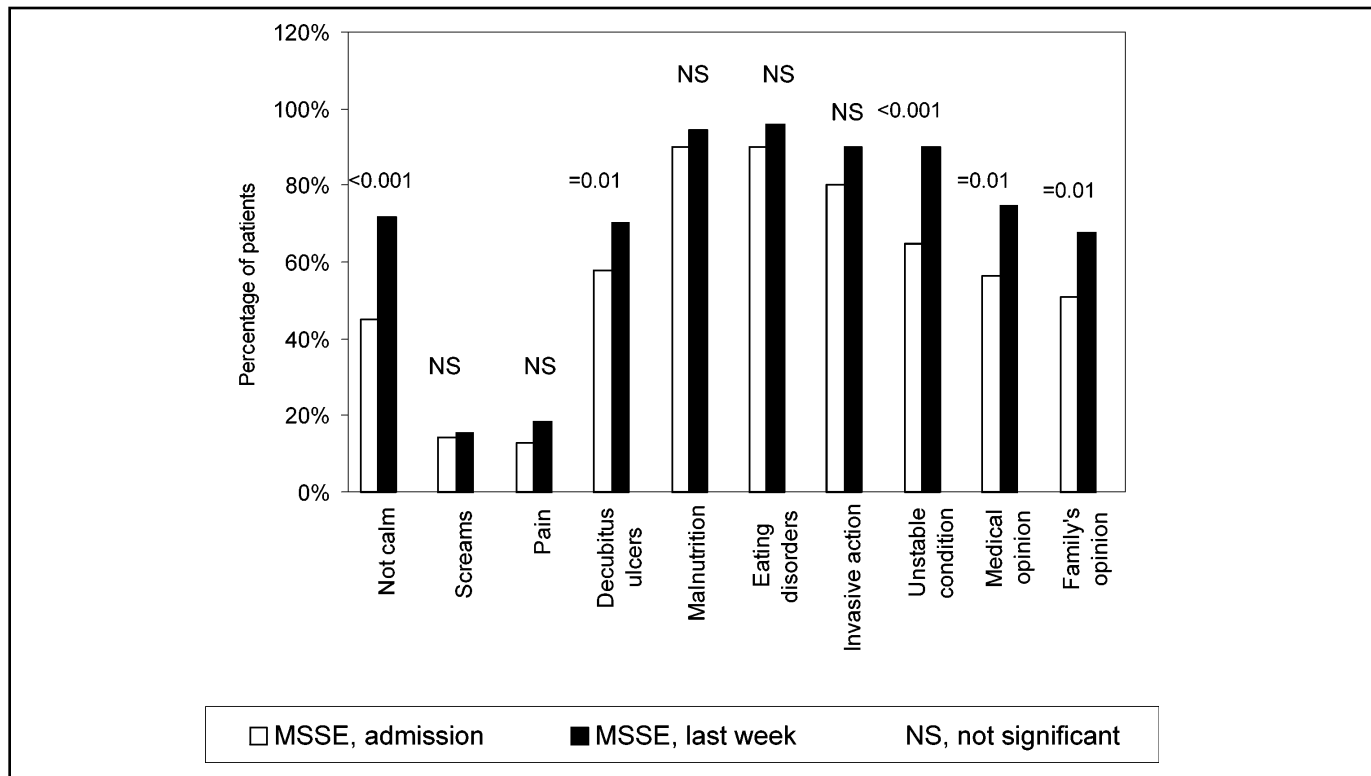


Figure 2. Changes in MSSE score for each item of the scale.

Diagnosis was based on the DSM-4 revised criteria for dementia.¹⁵ Patients were eligible for inclusion in the study if they suffered severe dementia interfering with verbal communication (Mini-Mental State Examination score of 0/30)¹⁶ and complete dependence in activities of daily living (ADLs) and functional movement (Functional Independence Measure score of 18/126).¹⁷ We included patients diagnosed as having Alzheimer's disease, multi-infarct dementia, post-stroke dementia, and dementia of unknown origin. The study was authorized by the local ethics Helsinki committee, and informed consent was obtained from families and caregivers. Only data for those patients who died while on the ward were included in the final analysis.

Level of suffering was evaluated using the MSSE each week following admission to the ward. The MSSE consists of 10 items relating to patient characteristics as well as the perception of his or her condition by medical staff and the patient's family (Table 1). Each item is

scored as 0 (No) or 1 (Yes). Total score ranges from 0-10 with high scores reflecting higher degrees of suffering. The scale has been shown to be valid and reliable,¹⁴ is brief and friendly, and takes less than 10 minutes to administer. We also recorded other laboratory (hemoglobin, albumin, cholesterol) and clinical data relevant to each patient's condition (i.e., presence of a feeding tube, use of psychotropic drugs, analgesics, or antibiotics, fever, or infection). Comparisons between the MSSE results (low, medium, or high degree of suffering) with regard to demographic and clinical variables were performed using analysis of variance (ANOVA), the Kruskal Wallis nonparametric test, and Fisher's exact test where applicable. Statistical significance was set at 0.05. SPSS 11.0 for Windows (SPSS Inc., Chicago, IL) was used for data analysis.

Results

Over a two-year period of study,

158 end-stage dementia patients were admitted to the geriatric unit from various other acute care departments in the hospital. Most of these patients were transferred following severely disabling stroke, hip fractures, or severe deconditioning due to recent pneumonia or urosepsis. The medical condition stabilized in 87 patients, who were then discharged to their previous living arrangements or to other nursing facilities. The remaining 71 patients (28 women, 43 men) died while on the ward. These 71 patients were included in the final analysis. Mean age of subjects on admission was 82.9 ± 8.0 , and mean survival (time of admission to death) was 38.1 ± 5.1 days (range 28.2-48.1 days).

Mean MSSE admission score was 5.62 ± 2.31 , increasing to 6.89 ± 1.95 during the last week of life ($p < 0.0001$). The percentage of patients with low- (0-3) and mid-range (4-6) MSSE scores decreased during the stay on the unit from 59 percent to 37 percent, while the percentage of those in the high MSSE

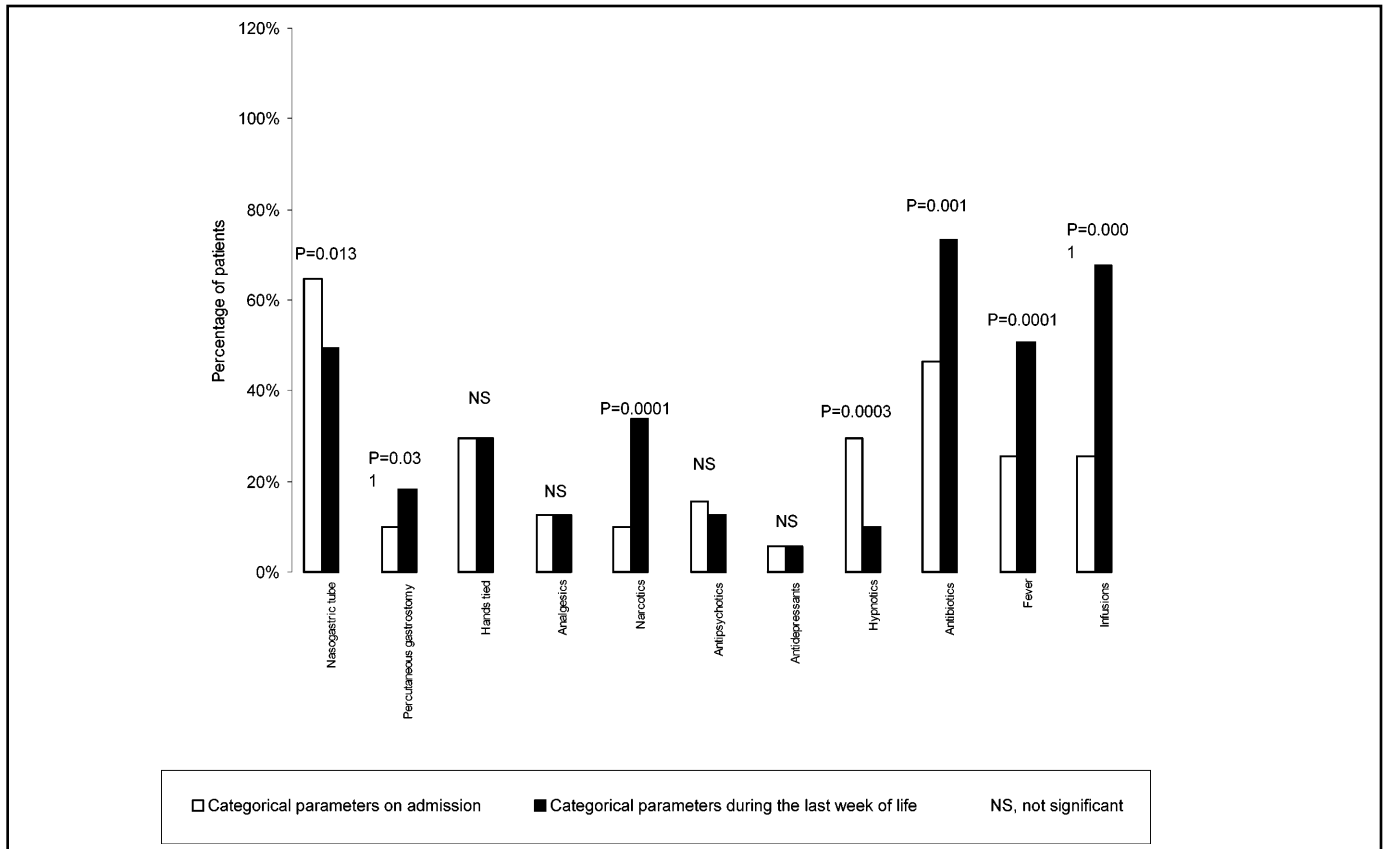


Figure 3. Clinical parameters associated with patients' conditions during hospitalization.

score (7-10) group increased from 41 percent to 63 percent. In fact, most patients (45 of 71, or 63 percent) died with an MSSE score in the high range, while only 7 percent died with a low MSSE score. These differences were statistically significant ($p < 0.001$) (Figure 1).

Compared with admission MSSE scores, a significantly greater number of patients scored in the mid and high MSSE ranges during the last week of life (Figure 2). During the last week, 71.8 percent of the patients were found to be agitated ($p < 0.001$), 70.4 percent suffered pressure sores ($p = 0.01$), 90.1 percent were in an unstable medical condition ($p < 0.001$), 74.6 percent were perceived as suffering by the medical staff ($p = 0.01$), and 67.6 percent were perceived as suffering by the family ($p = 0.01$). In addition, 15.5 percent were screaming, 18.3 percent were in pain,

94.4 percent were malnourished, 95.8 percent had eating problems, and 90.1 percent had undergone an invasive medical procedure during the last week of life. However, these differences were not statistically significant compared with baseline MSSE scores.

Clearly, at least a part of the increasing level of suffering could be attributed to a deteriorating medical condition. This was reflected by decreasing albumin levels (from 2.83 ± 0.51 g/dL to 2.59 ± 0.53 g/dL, $p < 0.001$), cholesterol (from 144.82 ± 42.69 mg/dL to 126.99 ± 46.9 mg/dL, $p = 0.0001$), and hemoglobin (from 11.06 ± 1.68 g/dL to 10.84 ± 1.96 g/dL, $p = 0.029$). Moreover, a statistically significant number of patients were febrile during last week of life and were treated with intravenous fluids, antibiotics, and narcotics. No significant differences were recorded with regard to use of physical restraints, analgesics,

antipsychotics, or antidepressants during the stay on the ward (Figure 3).

Physical pain was observed in 12.8 percent of patients on admission and in 18.3 percent on the last day of life. Non-narcotic analgesics were used in 12.7 percent of patients on admission and in 12.8 percent of patients on the last day of life, while narcotic analgesics were used in 9.9 percent and 33.8 percent, respectively. Percentage of patients who had their hands restrained remained unchanged during stay (29.6 percent).

Discussion

Assessment of suffering is extremely important in end-stage dementia patients, who cannot communicate their physical needs, understand treatment options, articulate their emotional needs, or express suffering at the end of life.¹⁸ Several aspects of this study may

provide guidance in assessing levels of distress in this population. First, MSSE scores improved over the course of the hospital stay for the low and medium MSSE groups, but unfortunately, they increased for those in the high MSSE group (Figure 1). This suggests that most end-stage dementia patients (63 percent) die while experiencing a high level of suffering, and that the number of patients experiencing extreme suffering increases significantly after admission.

Second, despite palliative efforts by experienced staff to ease the patient's condition, the care team is failing to minimize the suffering of persons dying with advanced dementia. Suffering scores rose despite the significant increase in use of narcotic analgesics (from 9.9 percent on admission to 33.8 percent on final measurement). This suggests that pain medication was not underprescribed in our population and that other steps may be needed to ease the suffering of such patients.

Third, the MSSE scale grossly defines three different levels of MSSE scores. As such, it can be used to monitor the extent of suffering so that inadequate medical or nursing treatment, negligence, and mistreatment^{19,20} can be detected, and steps can be taken to change treatment protocols and diminish the patient's level of suffering.

Active euthanasia could be used to end suffering but is considered unacceptable by most caregivers and medical staff and is prohibited by law in most countries. A different approach is to encourage more aggressive palliative medical and nursing care to prevent malnutrition, decubitus ulcers, infections, and other disorders that can be treated in patients experiencing higher levels of suffering. We believe that reductions in the levels of suffering in end-stage dementia patients can be achieved, at least in part, by better medical and nursing care, although this hypothesis needs to be proven by further research.

Finally, the MMSE approach is in accordance with the concept of suffering

as described by Cassell,²¹ encompassing not only psychological distress and spiritual concerns but also various aspects of physical pain.

Conclusion

Limitations of the study emerge due to differences of opinion regarding the definition and nature of suffering. We attempted to assess suffering from a more objective standpoint rather than using the classic, difficult-to-quantify subjective approach. Some may argue that establishing a clinical diagnosis of suffering is impossible, and others believe that people with end-stage dementia exist in a persistent vegetative state without sensation, perception, or emotion. However, it is unlikely that the association between subjective suffering and objective clinical tools is the same in patients with end-stage dementia as in those at a less advanced stage of disease.

We conclude that a substantial number of end-stage dementia patients die while experiencing a high level of suffering as evaluated by the MSSE. Routine use of the MSSE would improve awareness and facilitate treatment strategies aimed at diminishing the level of suffering of end-stage dementia patients.

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